What? We explored the definition of feedback and the types, extent, importance of and satisfaction with feedback given by researchers to Patient and Public Involvement (PPI) representatives on their contributions.

Who? Six regional ‘PPI in Research’ groups in the East of England were involved. Researchers, PPI group leads and PPI representatives provided information about feedback through an online survey, interviews, focus groups and audit.

Why? PPI representatives do not routinely receive feedback. Local PPI group tools and regional guidance have been co-designed to help PPI group leads and researchers prepare and deliver feedback to their PPI representatives.

“...constructive and honest feedback increases my confidence and makes me feel that my input is worthwhile” (PPI Representative)
Key Findings
Feedback was found to have different meanings; firstly, an acknowledgement of their contribution; secondly, to find out about the impact of that contribution on the research and thirdly, to be kept informed about the study success and progress. PPI representatives who receive feedback are motivated for future involvement and can use feedback as an opportunity to improve their learning and development. Researchers can also use feedback to reflect and record the impact that PPI has made on their project.

Reciprocal relationships between PPI representatives and researchers were found to be very important and face to face feedback was preferred. However, it seems there is no ‘one way’ to provide feedback, therefore, mutual feedback expectations should be discussed at the outset. PPI feedback needs to become a routine, on-going part of the research process with appropriate time and resources allocated.

The study findings include a number of suggested recommendations: all PPI guidance to include expectations around PPI feedback; PPI groups to consider implementing routine PPI feedback processes so that researchers know that feedback is part of PPI; funders to be encouraged to ask for reports, not only on general PPI, but also on the feedback to PPI representatives; researchers to be encouraged to include PPI feedback within their Gantt charts and timelines and a PPI lead, coordinator or researcher within the project needs to be identified to ensure that feedback takes place.

References

What is NIHR CLAHRC East of England?
The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England is a five year programme of applied health and social care research which focuses on the needs of people with complex problems, often vulnerable, when multiple agencies are involved in their care: young people, frail older people, those with dementia, learning disabilities, acquired brain injuries or mental ill health.

The CLAHRC East of England collaboration encompasses some thirty-six organisations, with research hubs in the Universities of Cambridge, Hertfordshire and East Anglia working closely with individuals and organisations involved in the whole care pathway.

Service users and carers are at the heart of what we do, in parallel with an ambitious public health research programme. Co-production and collaboration at all stages of the research process are fundamental to making a positive impact through applied health research.

More information and resources
Website: http://www.clahrc-eoe.nihr.ac.uk/2016/05/impact-patient-public-involvement-ppi-completing-feedback-cycle/
Email: e.j.mathie@herts.ac.uk

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